PROGRAM REVIEW

REHABILITATION SERVICES FOR PERSONS WITH A TRAUMATIC HEAD INJURY

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BC

Ministry of Health
Honourable Peter A. Dueck,
Minister

PROGRAM REVIEW

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EXECUTIVE SUMMARY

PURPOSE

This report proposes a plan of action to improve British Columbia's rehabilitation services for victims of traumatic head injuries. To help determine the best strategies for building on existing rehabilitation services, a Ministry of Health task group asked a broad range of service providers and representatives of persons with a head injury to identify the strengths and weaknesses of the rehabilitation system. It soon became apparent that there was a strong consensus -- indeed, almost unanimity -- about the main strengths and deficiencies.

BACKGROUND

Consultation Process. There is an increasing awareness across North America of the unique reintegration needs of persons who have sustained a traumatic head injury. Services have been described as in their infancy. While an array of treatment resources has been developed, many of the specialized services are only available to those with the financial resources available from insurance or other third-party settlements. British Columbia's Ministry of Health commissioned this report as a beginning step in the process of identifying ways to assist more citizens who require further rehabilitation but, due to financial barriers, have been unable to take advantage of a broader array of resources. The province of Ontario recently completed a similar process, also in recognition that this is an emerging social and health concern. Virtually all of those contacted for this report were very concerned about this issue and, in spite of extremely tight deadlines, made time to prepare and submit thoughtful written and/or verbal briefs. We thank them.

Nature and Extent of Head Injuries. About 50 or 60 percent of traumatic head injuries occur in motor vehicle accidents, with industrial and sporting accidents, assaults, and falls accounting for the remainder. Head injuries can produce a variety of problems, from paralysis and blindness to slowness of thinking, impaired judgement, and severe behavior disorders. Each year, an estimated 4,400 to 6,400 persons receive head injuries serious enough to warrant hospitalization, and 300 to 400 of these individuals suffer severe permanent disabilities.

DISCUSSION

Services Needed. British Columbia has services second to none in the areas of emergency roadside response, intensive and acute care, and initial medical rehabilitation following the acute care phase. Whether their injuries are mild, moderate, or severe, individuals with a head injury often require long term rehabilitation to recover some of their former physical, cognitive, and behavioral characteristics, or to adjust satisfactorily to permanent deficits in these areas.

Existing Services. A variety of rehabilitation services are currently available for head injured British Columbians: most notably, a very good acute care hospital system and some fine short term rehabilitation facilities. In addition, some long term rehabilitation services are available from the private sector. However, three main sets of problems exist:

1. Accessibility of *existing services:* There are two groups of persons with a head injury:

   - those hurt in motor vehicle or industrial accidents and who, because of their Insurance Corporation of British Columbia (ICBC) or Workers' Compensation Board (WCB) coverage, can afford to purchase long term rehabilitation services from the private sector; and

   - all others (probably about one-third of the severely injured), who go without long term rehabilitation because they were injured in sporting accidents or falls and do not have any special coverage.

   Other accessibility problems include:
   - lengthy waitlists at the short term rehabilitation hospitals;
   - a lack of information, among doctors, patients, and families, about the services that are appropriate and available; and
   - geographic barriers, especially for persons living in northern and interior areas of the Province.

2. Comprehensiveness of *existing services.* Certain services needed by those with a head injury are simply unavailable, even from the private sector. For example:
   - Appropriate residential care options, such as group homes, are not readily available. Consequently, many individuals — commonly in their early or mid 20s — are placed in extended care units designed for the elderly. Alternatively, they return home to their families, where their heavy care needs can lead quickly to caregiver burnout and frequently to complete family breakdown.
   - Vocational services, specialized therapy and educational services, and certain clinical services are also unavailable.

3. Cost effectiveness of *existing resources.* Much of the funding for head injury rehabilitation comes from ICBC, in the form of no-fault benefits and court settlements. Although the Corporation's rehabilitation consultants oversee spending of no-fault benefits, they have no say in the spending of tort settlements--which sometimes reach $1 million or more. The recipients of

these awards often spend the money unwisely, on therapeutically questionable services. Within 5 years, 80 to 90 percent of them exhaust their settlements and then reenter the publicly financed health care system.

Other wastage occurs because:

- Most head injured patients lack professional case managers to guide them through the service system, and thus they may end up consuming inappropriate services.
- There is a lack of quality control in the system. Patients who purchase expensive services from the private sector have no way of knowing beforehand whether or not the agency with which they decide to deal is legitimate, since no impartial inspection or accreditation takes place.

RECOMMENDATIONS

Priorities. A strategy to improve rehabilitation services for the head injured should reflect the following priorities: (1) Improve access to the existing range of services. (2) Develop a more comprehensive range of services. (3) Promote accountability and cost-effectiveness.

Short Term Proposals. In accordance with these priorities, this report identifies several steps the Government could consider taking to improve head injury rehabilitation in British Columbia. A summary of these proposals follows.

SHORT TERM RECOMMENDATIONS

Priority

1. *Improve access to existing range of services.*
   a. Develop information packages for physicians, community health care staff, patients, and families.
   b. Promote outreach/consultation from selected rehabilitation hospitals.
   c. Establish "help line" for families.
   d. Purchase community-based residential and therapy services for non-ICBC/WCB clients.

2. *Develop a more comprehensive range of services.*
   a. Develop longer term rehabilitation program at Pearson Hospital.
   b. Support development of group homes.
   c. Expand vocational programs and educational programs specialized in assisting persons with a head injury.

3. *Promote accountability and cost-effectiveness.*
   Establish accreditation team to clarify service standards.

4. Other—strengthen preventive efforts.
   Expand Counterattack; encourage use of bicycle helmets and programs targetted to home safety and motor vehicle safety.

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1.0 INTRODUCTION

1.1 Purpose of Review

This paper reviews the rehabilitation services currently available to residents of British Columbia who have a head injury in order to:

- identify strengths and weaknesses of the existing system of services; and
- propose a cost-effective, prioritized plan of action for improving the efficiency of the existing system and addressing the gaps in it.

1.2 Scope of Review

The review encompasses all "rehabilitation" services available to an individual, either adult or child, from the time of his first admission to an acute care hospital following a head injury.

Although the review focuses on injury resulting from trauma, or external force, many of its findings and recommendations apply equally to other forms of brain damage, such as that produced by stroke.

The review is concerned with "rehabilitation" primarily in the sense of restoring or maximizing health status, and hence it deals first and foremost with health care services falling within the purview of the Ministry of Health. However, when appropriate, the review also mentions certain social and economic issues (e.g., job training) that bear directly on the overall rehabilitation process.

1.3 Methodology

A task group with representation from relevent Ministry programs (see *Appendix A)* was assigned on November 23, 1987 to complete this review. This task group studied the available literature on head injuries, with particular attention to recent developments in other jurisdictions. It also undertook as much public consultation as time limitations would permit, meeting with and/or receiving written briefs from a cross section of service providers and representatives of the head injured. *Appendix B* outlines the groups involved in this consultation process, and *Appendix C* lists the questions they were asked to consider.

2.0 BACKGROUND

2.1 Overview of Current Services in British Columbia

A wide range of head injury rehabilitation services is currently available in British Columbia. It is beyond the scope of this paper to catalogue these services exhaustively, but the following is a "broad brush" overview of some of the major agencies now involved in this field.

Ambulances and General Hospitals. These provide emergency and acute care throughout the Province.

Rehabilitation Hospitals. Five free-standing rehabilitation hospitals (428 beds) and eleven rehabilitation units in acute care hospitals (225 beds) provide short term inpatient and outpatient rehabilitation — principally for the physically disabled, however, rather than specifically for the head injured. Major rehabilitation hospitals making a particular effort to address the very special needs of persons with a head injury include:

- *G. F. Strong Rehabilitation Centre in Vancouver:* This Provincial referral centre has a brain injury program which generally uses about 20 to 25 of the Centre's 150 beds. It also has an outpatient program.
- *Gorge Road Hospital in Victoria:* Some of the 23 beds in the neurological unit of this regional rehabilitation centre serve head injured persons from Vancouver Island.
- *Sunny Hill Hospital in Vancouver:* This is a 75 bed facility which provides comprehensive short term rehabilitation services to children, including some with head injuries, from throughout British Columbia.

Outpatient Rehabilitation. Limited outpatient services for the head injured are available from some rehabilitation hospitals and units. Outpatient services can also be purchased from a number of private consultants such as:

- *Waldee Services Incorporated:* Based in Coquitlam, this firm offers one-to-one, fee-for-service counselling in cognitive and practical skills to head injured adults and children in the Lower Mainland, Vancouver Island, Williams Lake, and Prince George.
- *F. Spellacy and Associates Limited:* Located in Victoria, this fee-for-service operation provides neuropsychological services and vocational assessments to adults and children.

Residential Care. A variety of institutional and community settings serves the head injured, including:

- *Extended and Intermediate Care Facilities.*
- *Riverview Hospital:* This psychiatric facility is the single resource capable of accommodating persons with severe behavior problems.
- *Privately-operated facilities in Vancouver:* L. and T. Services Limited (6 beds) and the Cheshire Homes Society of British Columbia (6 beds)

provide community living arrangements for persons with a head injury, including support programs.

Community-Based Programs. These include:

- *Home Care and Respite Services*--delivered through the Ministry's Continuing Care Division.
- *Vocational Assessment and Counselling*--available in Vancouver on a fee-for-service basis from West Coast Work Ahead Projects Corporation (Headwork).

Insurers/Service Providers. The two agencies most involved in paying for rehabilitation services for the head injured are:

- *The Insurance Corporation of British Columbia (ICBC):* For motor vehicle accident victims, the Corporation pays: (a) medical and rehabilitation benefits of up to $100,000 on a "no-fault" basis, and (b) court settlements—sometimes exceeding $1 million—in favour of people found to be only partly at fault, or completely blameless, for their accidents. The Corporation's Rehabilitation Department currently has eight "rehabilitation coordinators" to manage the no-fault funds and a growing caseload — now numbering 640 — of claimants with a head injury.
- *The Workers' Compensation Board (WCB):* WCB funds and/or provides rehabilitation services needed by individuals who have received head injuries through industrial accidents. The Board handles some 235 head injury claims annually, about 50 of which involve very seriously hurt survivors.

Advocacy and Support Groups. The British Columbia Head Injury Association was formed in 1982 by concerned families and professionals in order to provide a network of information and support for the head injured and their families. Local chapters are located in Victoria, Kamloops, the Okanagan, Nanaimo, and Prince George.

Families. Relatives supply an enormous portion of all the rehabilitation/support services delivered to persons with a head injury. Many young adults return to their parents' home after they are released from hospital, regardless of where they lived prior to the accident.

2.2 The Nature of Head Injury

How head injury occurs. Traumatic head injury is caused by a blow to the outside of the head. About 50 or 60 percent of these injuries occur in motor vehicle accidents. The remainder occur in industrial and sporting accidents, assaults, and falls. Bicycle accidents and falls are especially common causes among children.

A significant percentage of head injury accidents are alcohol-related.

Who is injured. In British Columbia, as in other jurisdictions, young males experience the majority of head injuries. Sixty percent of those injured in motor vehicle accidents are between the ages of 14 and 30 at the time of their accidents, and males outnumber females three to one.

Effects of head injury. When the head is hit with sudden force, the brain may tug and twist on the brain stem. The brain may then rebound against the opposite side of the skull. This twisting and rebounding can inflict a variety of diffuse damage to the brain — damage that may be exacerbated by any swelling or bleeding which ensues. A serious head injury usually results in a loss of consciousness, which may last anywhere from a few minutes to weeks or even months.

Traumatic head injuries can produce a variety of problems, including:

- *Physical deficits:* e.g., paralysis; spasticity; loss of bladder/bowel control; speech, vision, or hearing impairments; seizures.
- *Cognitive impairments:* e.g., inability to concentrate, remember, or understand ideas; slowness of thinking; impaired judgement.
- *Personality changes:* e.g., mood swings, irritability, or depression; aggressive, abusive, or impulsive behavior; loss of inhibitions; sexual dysfunction.

The precise mix of problems that a given injury produces depends on several factors. In general, the more diffuse the physical damage to the brain and the longer the coma and "post-traumatic amnesia," the more varied and serious the resulting problems will be. However, even a relatively "mild" injury — one which results in a very brief (or no) coma and no physical disabilities — can cause changes in thinking and personality sufficient to impair the patient's ability to pursue his career/education or continue established relationships. Sometimes the full extent of these functional disabilities and behavior changes become apparent to the patient, his family, and his employer/teachers only after a period of months or years, and the connection of these changes to the head injury may never even be recognized. Persons with head injuries, especially moderate or severe injuries, are at high risk of family breakdown, loss of employment or dropout from school, psychiatric problems, alcohol and drug abuse, additional accidents, and trouble with the law.

2.3 Dimensions of the Problem

Growing Numbers. The number of head injured persons is increasing steadily. Advances in emergency care are saving many individuals who in previous years would have died. Additionally, these survivors tend to have more severe injuries and impairments than we have seen in the past.

Incidence. We know that in 1985/86, 4,398 individuals were admitted to the Province's hospitals with a primary diagnosis relating to head injury. An additional 845 individuals were admitted with head injury as a secondary diagnosis, meaning that they had another, more significant injury, in addition to their head injury. These figures understate the extent of the problem, however, because they do not include persons whose head injuries went unrecognized or who were seen in emergency rooms but sent home without being admitted as inpatients. Adjusted to reflect these missing cases, the figures would likely be reasonably consistent with the scientific literature and reports from other jurisdictions (e.g., Ontario) which estimate a total annual hospital admission rate for head injuries of 2.2 cases per 1,000 population (or about 6,380 cases per year in British Columbia).

Severity. Hospital admission data do not indicate the severity of injuries. Reliable criteria for measuring severity have not yet been developed. Consequently, it is impossible to determine with certainty how many persons experience minor, moderate, or severe injuries. Applying recent Ontario estimates to British Columbia, however, suggest the following "ballpark" figures:

Outcome (1 month after injury)	*Number Per Year*
- Death	123 to 179
- Severely Disabled	273 to 395
- Moderately Disabled/Mild	4,002 to 5,806
TOTAL	4,398 to 6,380

Discussions with key agencies suggest that these estimates, though rough, are not unreasonable. The Insurance Corporation of British Columbia (ICBC) reports that in 1987 its Rehabilitation Department served approximately 180 new individuals suffering significant physical or mental impairments due to head injury. Since motor vehicle accidents account for 50 to 60 percent of head injuries, it seems safe to assume, as the British Columbia Head Injury Association does, that there are at least 300-400 new survivors of moderately or extremely severe head injuries each year in British Columbia.

2.4 The Process of Head Injury Rehabilitation

History/Trends. Head injury rehabilitation programs have multiplied rapidly in recent years, in response to the increasing numbers of young persons who are incurring serious head injuries and then facing normal lifespans in varying states of disability. In 1980, 15 head injury programs operated in the United States, but by 1985 the number had grown to 500. This trend reflects a growing conviction among families and service providers that more can and must be done to restore these young people to their highest possible level of functioning.

Objectives. Rehabilitation aims to assist the injured person to attain his maximum potential for normal living — physically, psychologically, socially, and vocationally. Victims of serious brain injuries can rarely be "cured" altogether; for most, their lives will never be exactly the same again. To the extent that the brain is able to recover functions, rehabilitation represents a nurturing and relearning process. To the extent that faculties are not recoverable, rehabilitation involves providing victims with strategies to manage their lives in different ways.

Ideal Model. It is important to remember that, in many ways, rehabilitation of the head injured is still in its infancy: many of the existing rehabilitation programs for the head injured are relatively new and have not been evaluated scientifically. Nevertheless, broad consensus does exist among service providers and consumers, both in British Columbia and in other jurisdictions, about the key characteristics of any service system for this clientele:

a. *Services should be **comprehensive**.*

Rehabilitation of the head injured requires a full continuum of services, from the time of the accident to community reintegration. *Appendix D* provides a brief summary of these services.

To be truly comprehensive, the service continuum must incorporate the expertise of a broad range of professional disciplines, including: specialists in neurosurgery and physical medicine; neuropsychologists; nurses; occupational therapists; physiotherapists; speech-language pathologists and audiologists; and social workers.

b. *Services should be **accessible.***

In the ideal model, there would be no obstacles to obtaining needed services. In other words:

i. The model would overcome financial barriers. Clients would access services on the basis of health status and potential for improvement, not ability to pay.
ii. The model would avoid lengthy waitlists. Active rehabilitation should begin as soon as possible after the injury. As the client progresses, he should be able to move without delay through the appropriate sequence of services. Otherwise, the momentum of his recovery may slow; he may even begin to regress.
iii. The model would avoid regional service gaps, and treat clients as near to their eventual homes as feasible. This is important because the participation of family and friends can expedite the rehabilitation process. Moreover, some clients are unable to adapt life skills learned by rote (e.g., the use of public transportation services) from one setting to another.
iv. The model would overcome professional and public ignorance about the rehabilitation programs that are available and appropriate for the head injured.

Ideally, rehabilitation services should also be "re-accessible" to clients who have been discharged on previous occasions. Over the course of several years, clients tend to reach "plateaus," from each of which they may eventually move on after a period of rest and consolidation.

c. *Services should be **cost-effective.***

The model system would ensure: (a) that the limited funds available for head injury rehabilitation were allocated among the most effective possible mix of programs; (b) that each patient had an individually tailored and professionally managed service plan; and (c) that auditing and evaluation of services occurred regularly.

d. *Other.*

The model system of services for the head injured would go beyond post-injury rehabilitation per se: it would place a strong emphasis on prevention.

3.0 DISCUSSION

3.1 Strengths and Weaknesses of Current Services

The consultation process revealed that British Columbia's services for the head injured compare favorably with those of most other jurisdictions, but that they are still a considerable distance from the "ideal model" sketched earlier in this paper. More specifically:

a. *In terms of comprehensiveness —*

Strengths

British Columbia has a relatively good range of services, compared to many other jurisdictions, and the situation is improving. For example:

i. *Availability of emergency and acute care.* The Province's life-saving services are generally acknowledged to be second to none.

ii. *Availability of short term, hospital-based rehabilitation.* The intensive short term rehabilitation services provided through institutions such as the G.F. Strong Centre and Gorge Road Hospital are of the highest quality. The programs are delivered by well qualified, highly motivated inter-disciplinary teams.

iii. *Availability of private sector services.* British Columbia has a wider range of services available through the private sector than many other jurisdictions. These services include specialized therapy, such as cognitive retraining by neuropsychologists, as well as transitional group homes and vocational counselling.

This private sector "industry" has arisen primarily in response to ICBC's superior no-fault coverage for medical and rehabilitation services (maximum of $100,000, compared to $5,000 in Alberta and $25,000 in Ontario) and encouragement of high liability insurance policies (80 percent of motorists purchase coverage of at least $1 million). As a result of these arrangements, the majority of British Columbia's head injury victims — those hurt in motor vehicle accidents — have resources to purchase the often very expensive therapeutic services offered for sale by the private sector. The Workers' Compensation Board is another important purchaser of these private sector services.

Weaknesses

Notwithstanding these important strengths, certain critical services are still unavailable in British Columbia. B.C.'s experience is consistent with other jurisdictions in that service development has focused on the initial medical rehabilitation. Longer term reintegration resources have not evolved due, in part, to the individualization of approach that is required and because we are continually learning about what is possible. For example:

i. *Lack of long term inpatient rehabilitation.* The Province has no longer term, "slow stream" rehabilitation facilities for persons unable to handle intensive short term rehabilitation such as that offered at the G. F. Strong Centre.

ii. *Lack of residential care options.* With the exception of privately-operated group homes in Vancouver and Victoria, the Province has no non-institutional living arrangements designed expressly for the head injured. As a result, many of these individuals — commonly in their early or mid-20s — are in extended care units catering to the elderly. Alternatively, they return home to their families, where their heavy care needs can lead quickly to caregiver burnout and frequently to complete family breakdown.

iii. *Lack of community re-entry services.* Even in the metropolitan areas, suitable vocational training, life skills programs and self-help support programs are usually unavailable.

iv. *Lack of highly specialized professionals.* Some of the professionals needed for rehabilitation of the head injured are in short supply, especially in remote areas. This is particularly true of neuro-psychologists (who take the lead role in cognitive assessment and retraining) and speech-language pathologists and audiologists.

v. *Lack of certain specialized clinical programs.* A limited number of very specialized clinical programs, which are operating elsewhere, apparently with good results, are not yet available in British Columbia. These include behavior management and "coma management" programs.

b. *In terms of **accessibility**—*

Strengths

Reduced financial barriers. On balance, access to the services which do exist in British Columbia is fairly good compared to access in some other areas. This is mainly because financial barriers to services have been substantially removed for the majority of persons receiving head injuries.

The removal of these barriers has been accomplished by:

- public health insurance, in the case of emergency, acute, and extended care for all residents of the Province;
- ICBC's excellent no-fault coverage, as well as generous court settlements, in the case of longer term rehabilitation for persons injured in motor vehicle accidents; and
- WCB coverage, in the case of longer term rehabilitation for persons injured in industrial mishaps.

Weaknesses

Despite the removal of many financial barriers to care for the majority of head injury victims, accessibility to the existing services is still inadequate for a large number of persons with a head injury. The remaining obstacles include:

i. *Financial barriers.* Persons who are injured other than in a motor vehicle or industrial accident, and who thus lack ICBC/WCB coverage, are normally unable to afford the expensive post-hospital rehabilitation services (e.g., transitional housing programs, cognitive retraining, occupational therapy) that might prove beneficial to them. These uninsured persons probably constitute about one-third of the total group receiving moderate/severe head injuries each year. (Even for individuals who are covered by ICBC, a catastrophic injury can quickly consume the $100,000 available on a no-fault basis.)

ii. *Informational barriers.* Head injuries can be very difficult to diagnose. General practitioners and emergency room physicians may sometimes be unaware of the specialized services that are available for dealing with such cases and the follow-up support available to victims and their families. A similar lack of information also prevents many teachers, families, and patients themselves from seeking and accessing existing services when it would be appropriate for them to do so.

iii. *Waitlists.* Not all patients can access the few excellent rehabilitation facilities which presently exist. Due to resource limitations, competing priorities and lack of specialized programs to assess and treat these individual cases, these facilities have established strict admission criteria. Their waiting lists are long.

iv. *Geographic barriers.* To enter hospital rehabilitation programs, individuals from northern and interior regions of the Province often must travel long distances, leaving their families and familiar surroundings behind. As well, many of the existing "community" services (e.g., residential, vocational, neuropsychological) are available only in the Lower Mainland or Victoria.

c. *In terms of **cost-effectiveness** —*

Strengths

Competent rehabilitation hospitals. There is general agreement that British Columbia's rehabilitation hospitals offer an excellent, highly effective service, and that they allocate their limited resources in a competent and professional fashion.

Weaknesses

Although individual hospitals are doubtless providing good value for money, some of the services that are available outside of hospitals may be consumed inappropriately or be of poor quality:

i. *Misuse of court awards.* Court settlements paid by ICBC to persons hurt in motor vehicles due to the negligence of others are not necessarily subject to any kind of professional management and are often spent unwisely. Although ICBC's rehabilitation consultants oversee spending in "no fault" claims, they have a limited say in the spending of lump sum tort settlements. Moreover, although courts have the authority to establish "structured settlements" (annuities) instead of approving one-time grants, they currently do so in only a small minority of cases. Without a structured settlement or long term plan, the injured person frequently spends the money — which may reach $1 million or more in the case of a serious injury* — on extremely expensive, but therapeutically questionable, services. In fact, ICBC estimates that 80-90 percent of these individuals have exhausted their settlements within 5 years — at which time they reenter the publicly financed health care system (e.g., extended care).

ii. *High cost of adversarial system.* A large portion of the ICBC court settlements also go astray during the litigation process. It is not an unusual practice for plaintiffs' lawyers to work on a contingency basis, taking as their fee a pre-determined share of whatever award is won. This share can amount to between 30 and 50 percent of the final award.

* *The size of the awards is influenced by the apparent shortage of specialized head injury programs in British Columbia. Courts often conclude that the only way of ensuring access to appropriate treatment is to make the settlement big enough so that the plaintiff can attend expensive programs in the United States. Many of the services available in the United States are marketed very aggressively but lack sound outcome data to justify the extraordinarily high fees charged for them. One program in Seattle, for example, has an annual cost of $312,000 in U.S. funds and a recommended program duration of 2 years.*

iii. *Lack of evaluation/accreditation.* It is not clear that the large sums being spent on services marketed by agencies (both in British Columbia and in the United States) are in all cases being well spent. Little evaluation or accreditation takes place with respect to these services, some of which could be considered unproven therapies which require evaluation.

iv. *Inappropriate use of services.* The shortage of programs tailored specifically for the head injured drives some clients into arrangements that may not be particularly effective or efficient. For example, many persons with a head injury are placed in extended care units, where the per diem costs are relatively low but the rehabilitation program minimal. Other individuals develop behavior problems and, without treatment, wind up in jail.

v. *Lack of coordination/case management.* Except for those in receipt of ICBC's no-fault insurance benefits, head injured patients have no one to guide them through the fragmented service system which presently exists. As a result, they may go without services that would be very beneficial or, conversely, consume services that they do not need.

d. *Other Strengths and Weaknesses*

The Province has taken important steps in prevention, through initiatives such as Counterattack, seatbelt legislation, and the mandatory use of helmets by motorcycle riders.

3.2 Developing a Strategy for Head Injury Rehabilitation

Potential Initiatives. It would be relatively straightforward to prepare a list of initiatives which could potentially improve the lot of those with a head injury. Ideally, of course, one would strive to remedy each and every one of the "weaknesses" identified earlier. The objective would be a fully insured, comprehensive system of accredited and monitored services, delivered on an equitable basis in all regions, and encompassing a cost-effective blend of short and long term rehabilitation.

Practical Constraints. However, it is neither feasible nor desirable to attempt, at this point, to create the "perfect" system of head injury rehabilitation in British Columbia. First, we do not yet have a clear enough picture of the problem. For example, we lack reliable data about the exact number of clients, how serious their injuries are, where they live, and what their potential for improvement is. Second, no one knows for certain what the best solutions are for this group. Rehabilitation of the head injured is a comparatively new area of specialization and study: in many ways, "uncharted territory."

Third, even if we had a perfect understanding of both the problem and the optimum solution, we would be constrained by the fact that our society is limited in what it can spend on health care. The resources devoted to head injury rehabilitation (which can be an extremely costly process) will, in part or in full, need to be diverted from other worthy causes.

Guiding Principles. Mindful of both the needs and constraints in this area, the task group developed a set of broad principles to guide its selection of short and long term recommendations:

a. *Recognize uniqueness.* Initiatives must recognize that the head injured constitute a unique group with very special needs. It is fundamentally untherapeutic to group the head injured with the mentally ill, the mentally handicapped, or the aged.

b. *Minimize intervention.* Initiatives should reinforce the invaluable contributions of families, local support groups, and volunteers. Government action should facilitate, not replace, informal rehabilitation activities. Wherever possible, community-based services should receive preference over institutional services.

c. *Give priority to improving existing services.* Short term initiatives should centre on obtaining better value from existing resources, rather than on major new resource commitments. Priority #1 is to improve the efficiency, effectiveness, and availability of the services that already exist.

d. *Focus first on moderately injured.* In the short term, the best investment of limited rehabilitation dollars would appear to be with the moderately injured. Many of these individuals have the potential to function independently or semi-independently but are not currently doing so due to a lack of service. The failure to provide rehabilitation services to the moderately injured could be a false economy because their continuing dependency could cost the system considerably more in the long run. This does not mean that we should ignore those with severe or mild injuries. On the contrary, with proper stimulation, the severely injured can often achieve significant improvements in their quality of life. And the mildly injured represent a "hidden" problem of undetermined, but potentially major, importance.

e. *Ensure consistency with overall Government plans.* Initiatives should be consistent with the long range goals of both the Ministry and the Government as a whole. More particularly, they should reflect and embody initiatives to strengthen families, develop accessible services in all regions and promote a community-based approach rather than a move toward institutionalization. Initiatives should also take account of developments in related program areas (e.g., the redesign of the mental health system).

4.0 RECOMMENDATIONS

4.1 Short Term Strategies (within 12 months)

a. *To increase **comprehensiveness** of services—*

i. *Develop a longer term ("slow stream") rehabilitation facility.* Establish 15 beds designated for a special brain injury program at Pearson Hospital in Vancouver.

ii. *Develop community residential facilities.* Encourage further development of at least two 4-6 bed "transitional" group homes in 1988/89 to be available to clients whatever their sources of funding. The homes would aim to equip individuals with the skills needed to resume independent or semi-independent living.

iii. *Expand vocational services.* Rather than starting a new vocational program itself, the Ministry should initially undertake to contact organizations like Goodwill Enterprises concerning the possible extension of its vocational programs into designated communities, and the Ministry of Advanced Education and Job Training, concerning the possible development of special vocational and educational services for the head injured.

b. *To improve **accessibility** to services—*

i. *Purchase community rehabilitation services for uninsured persons.* Establish a fund to purchase longer term, community-based rehabilitation services from private and non-profit service providers on behalf of uninsured clients (i.e., those injured other than in motor vehicle or industrial accidents).

Comments:

- The purchased services could include transitional housing; cognitive retraining; and regimes of occupational or physical therapy and counselling.
- A small team of respected professionals (e.g., from the G.F. Strong Centre, Gorge Road Hospital, and Sunny Hill Hospital) could be established to manage the fund — i.e., to select both clients and service providers.

ii. *Develop information packages.* Prepare information packages about head injuries and available resources for distribution to: emergency room physicians and general practitioners; patients and families; and community-based health care workers. The Government could also participate in the establishment of a province-wide, toll-free "help line" for families.

iii. *Improve regional access to specialized expertise.* Develop consultative/ outreach programs from the G. F. Strong Centre (for adults) and Sunny Hill Hospital (for children) to hospitals throughout British Columbia.

c. *To improve* ***cost-effectiveness*** *of services—*

Establish a professional advisory and accreditation group. This body could define program and service standards, and ensure appropriate evaluation of all new programs. Its members should be drawn from the main rehabilitation hospitals and the University of British Columbia.

d. *Other.*

Pursue preventive efforts with even more vigor than at present. Expand Counterattack; encourage/require the use of bicycle helmets; and promote targetted home safety programs.

4.2 Implementation Issues

Priorities. The task group ranked its short term recommendations on the following basis:

- The first priority is to improve access to the existing range of services.
- The second priority is to develop a more comprehensive range of services.
- The third priority is to promote accountability and cost-effectiveness.

Revenues/Funding. The Government may wish to consider special revenue measures to fund the proposed services. An innovative technique employed in some parts of the United States is a $5 surcharge on fines for moving violations committed by motor vehicle drivers. This revenue strategy would have the added advantage of raising public awareness about the risk factors and costs associated with head injury.

4.3 Longer Term Strategies

In the longer term, it is recommended that consideration be given to the following initiatives:

a. *Assign central and regional planning responsibilities.* The Ministry of Health should develop standardized procedures for reporting head injuries so that we know exactly how many are occurring, why and where they are happening, and how severe they are. In addition, each of the eight new development regions (or other regionally-based structures, such as the Premier's Advisory Council on Persons with Disabilities) should take responsibility for identifying and prioritizing the needs of the head injured in each area of the Province.

b. *Move towards a regionalized network of services.* Each of the services listed in *Appendix D* should be available as near as feasible to the client's own region/home. Subject to the proposals of whatever regional planning structure is chosen, the first steps towards this model would likely involve:
   - the establishment of rehabilitation programs specifically for the head injured at Gorge Road Hospital in Victoria, as well as in the rehabilitation units of the Kelowna and Prince George hospitals;
   - the development of a regional case manager structure;
   - the gradual expansion of community-based services where numbers warrant; and
   - the development of localized follow-up services for persons with mild head injuries to ensure that their needs are recognized and met.

c. *Improve the management of court awards for head injuries.* Explore options for encouraging structured court settlements, alternate models for a legal fee cost schedule so that the huge sums awarded for bodily injury claims (about $400 million per annum through ICBC alone) are spent more wisely, and recipients do not prematurely become drains on the publicly financed health care system.

APPENDICES

APPENDIX A

MEMBERS OF THE TASK GROUP

Steering Committee

Dr. C. B. Henderson
Assistant Deputy Minister
Institutional Services

Mr. Paul Pallan
Executive Director
Policy, Planning and Legislation

Ms. Joyce Ganong
Executive Director
Continuing Care

Mr. Peter Van Rheenen
Acting Executive Director
Services to the Handicapped

Working Group

Mr. Jim Redford
Manager of Policy and Planning
Policy, Planning and Legislation

Dr. John Higgins
Medical Consultant
Hospital Programs

Ms. Deborah Shera
Program Consultant
Services to the Handicapped

Ms. Gina Klypak
Acting Consultant,
Home Nursing Care
Continuing Care Division

Ms. Lynda Farmer
Administrative Consultant
Hospital Programs

APPENDIX B

LIST OF ORGANIZATIONS AND INDIVIDUALS CONSULTED BY THE TASK GROUP

1. British Columbia Psychological Association
2. Workers' Compensation Board
3. Western Rehabilitation Society (G.F. Strong Rehabilitation Centre and Pearson Hospital)
4. Prince George Brain Injury Group (including families, physicians, and lawyers)
5. Greater Victoria Hospital Society (Gorge Road Hospital)
6. Sunny Hill Hospital, Vancouver
7. Waldee Services Incorporated (Community Rehabilitation Services), Coquitlam
8. Kelowna General Hospital (staff and private practice therapists)
9. Dr. Gur S. Singh
   Chairman, Section of Neurosurgery
   British Columbia Medical Association
   Kamloops
10. Dr. T. R. Deutscher
    Chairman, Section of Physical Medicine and Rehabilitation
    British Columbia Medical Association
    Nanaimo
11. Simpson Rehab Management Limited, Coquitlam
12. Dr. Theo van Rijn
    Specialist in Physical Medicine and Rehabilitation
    Shaughnessy Hospital
13. North and South Okanagan Head Injury Society
14. Lions Gate Hospital (Medical Day Centre)
15. British Columbia Society of Occupational Therapists

16. Physiotherapy Association of British Columbia

17. British Columbia Association of Speech-Language Pathologists and Audiologists

18. British Columbia Head Injury Association

19. Insurance Corporation of British Columbia

20. F. Spellacy and Associates Limited, Victoria

21. Cheshire Homes Society of British Columbia

22. Dr. Desmond P. Dwyer, Vancouver
(Primary care physician with professional interest in head injury)

23. Neil Squire Foundation, Vancouver

24. Registered Nurses' Association of British Columbia (ad hoc committee)

25. University of British Columbia Health Sciences Centre Hospital
(Head Injury Assessment Program)

APPENDIX C

PROGRAM REVIEW
REHABILITATION SERVICES FOR PERSONS
WITH A TRAUMATIC HEAD INJURY

GUIDELINES FOR SUBMISSIONS

1. *Scope* — The review concerns the entire continuum of rehabilitation services available to residents of British Columbia who suffer head injury as a result of trauma. It deals with all rehabilitation services available in the system--for both children and adults — from the time of a patient's first admission to an acute care hospital.

2. *Introduction* — Submissions should begin by providing a brief (2-3 pages maximum) overview of the organization's involvement in this area, e.g.:

   a. mandate/purpose;
   b. services provided;
   c. nature of clientele;
   d. scope of activity (geographic area covered, number of clients, staffing, annual expenditures).

3. *Analysis of Existing System* — Next, the submissions should describe briefly (5-6 pages maximum) the strengths and weaknesses of the overall system of services currently in place for the head injured.

   a. What are the most positive aspects of the current system?
   b. Are any major elements lacking in the current continuum of services?
   c. Are funds directed in a manner which delivers services in the most cost-effective way, or could we improve service delivery by reallocating funding?
   d. How serious are any deficiencies? How many persons are affected, to what degree, and with what result?

4. *Recommendations* — Submissions should conclude with a short (2-3 pages maximum) summary of the organization's recommendations for improving the system.

   a. Recommendations should be presented in order of priority.
   b. Recommendations should be pragmatic: they should reflect the fact that this a time of scarce economic resources.
   c. Recommendations should be as specific as possible: they should not simply identify goals; they should also suggest how those goals can be achieved.

APPENDIX D

REHABILITATION SERVICES FOR PERSONS
WITH A TRAUMATIC HEAD INJURY

IDEAL MODEL: SPECTRUM OF SERVICES AVAILABLE

Institution-Based Services

1. *Emergency and acute care:* includes sophisticated diagnostic techniques and advanced neurosurgical and medical procedures.
2. *Coma management:* prevents unnecessary complications and provides appropriate stimulation.
3. *Short term inpatient rehabilitation:* provides intensive physical, cognitive, behavioral, psychosocial, and vocational programming, usually for less than six months, to patients able to handle several hours of therapy each day.
4. *Long term inpatient rehabilitation:* provides a structured, "slow stream" program of stimulation and therapy, for 1-2 years (or longer where appropriate), to: (a) recently injured patients not yet ready for intensive rehabilitation, and (b) severely injured patients able to make functionally significant improvements on a very gradual basis.
5. *Behavior management units:* provide special settings (including secure settings) for handling individuals with behavior disorders.

Community-Based Services

1. *Short term outpatient rehabilitation:* provides specialized treatment for cognitive, behavioral, or other deficits to: (a) seriously injured patients discharged from inpatient units, and (b) mildly or moderately injured patients who do not require in-hospital care.
2. *Residential services:* includes: (a) transitional housing, which prepares clients for maximum independence by teaching home-based activities of daily living, such as cooking, budgeting, shopping, and leisure skills; and (b) a range of ongoing living arrangements, from small, heavily staffed group homes to supervised apartments.
3. *Day programs:* provide out-of-home activities for head injured individuals living in the community, e.g.: (a) vocational counselling and training; (b) sheltered work settings; (c) life skills training; and (d) recreation and socialization.
4. *Family support:* involves a variety of support for families, e.g.: (a) professional counselling and training; (b) in-home and facility respite care; and (c) mutual support groups.

APPENDIX E

SHORT TERM RECOMMENDATIONS

Priority

1. *Improve access to existing range of services.*
   a. Develop information packages for physicians, community health care staff, patients, and families.
   b. Promote outreach/consultation from selected rehabilitation hospitals.
   c. Establish "help line" for families.
   d. Purchase community-based residential and therapy services for non-ICBC/WCB clients.

2. *Develop a more comprehensive range of services.*
   a. Develop longer term rehabilitation program at Pearson Hospital.
   b. Support development of group homes.
   c. Expand vocational programs and educational program specialized in assisting persons with a head injury.

3. *Promote accountability and cost-effectiveness.*
   Establish accreditation team to clarify service standards.

4. *Other — strengthen preventive efforts.*
   Expand Counterattack; encourage use of bicycle helmets and programs targetted to home safety and motor vehicle safety.

APPENDIX F

"THE INVISIBLE HANDICAP" *

This paper was written by the mother of a teenage daughter who sustained a traumatic head injury in July 1987. The paper was submitted to the Ministry of Health in response to the program review of rehabilitation services for persons with a traumatic head injury and is published here with permission of the author. The opinions expressed in this paper are those of the author.

THE INVISIBLE HANDICAP

This paper points out some of the problems our family has had in getting information about head injuries, finding available resources in our community and getting their co-operation.

(ED. NOTE: An earlier version of this submission was written in January, 1988. Since that time, the author and her family have relocated, through a compassionate transfer by her husband's employer. They have moved to a community closer to the level of treatment required by their daughter in Vancouver. This submission was updated for the final report.)

My name is Q**. I am the mother of a 15-year-old daughter, S**, who was in a car accident in the summer of 1987. S had multiple head injuries as well as massive internal injuries. Two young people were killed in that same accident. The care S received at the regional hospital in our community was excellent — this includes the trauma unit in Emergency, Intensive Care, and Pediatric Special Care Unit.

When S was discharged from hospital at the end of August, 1987, she was in a wheelchair with limited movement on her right side and had mental problems as well. At that time we were told she possibly may remain in this condition forever or could improve. Fortunately, S has improved greatly physically and is doing well recovering from her head injuries.

Listed below are areas where we have encountered problems and suggestions which could help solve some of these problems.

1. REHABILITATION SERVICES

Opening of a Rehabilitation Unit in our community as soon as possible:

This would reduce costs to the Ministry of Health, I.C.B.C., and the families of patients, and would also keep families together. Having a basic rehabilitation unit in our community would not be a duplication of services available in Vancouver which are specialized services.

S was physically healed enough at the end of August to be discharged from hospital. The Rehabilitation Unit was not open. Therefore, we were given two options. The first was to send our 15-year-old daughter away to Shaughnessy Hospital or some such institution until her mental capabilities improved enough

*** The author requested anonymity for her daughter and family in order to provide them with some privacy. Letters have been used in place of their real names. In some cases, names of communities have been deleted for the same reason.*

so she would be accepted at G.F. Strong Rehabilitation Centre. The second was to take S home and see what improvements the future would bring.

We chose to keep S at home with the understanding she could be readmitted to hospital if we could not cope. I took a two week leave of absence from my work until "aides" were able to come into our home to care for her. The Social Services Department of the regional hospital arranged for the "aides." Without the help of the "aides" we would have had no option — we would have had to readmit our daughter to the regional hospital or have her sent to Vancouver. We knew we were not capable of giving S the specialized care she required. We are glad she was able to stay in our home community. Both our family physician and ourselves feel this greatly helped with her mental state at that time. Having S in Vancouver would have added more stress to her and our family.

Another recommendation would be to have the "aides" trained in some occupational therapy. I understand some have limited knowledge of physio-therapy. The physiotherapy department at the regional hospital has done a wonderful job with S's rehabilitation. This has been acknowledged by G.F. Strong Rehabilitation Centre.

It would be helpful if financial assistance or discounts could be made available for facilities such as the swimming pool, Y.M.C.A., and similar resources for recommended "outside" physio and occupational therapy once the head injured person is at home.

2. <u>A GENERAL HEAD INJURY INFORMATION CENTRE</u> - through regional hospital or Public Health

Once our daughter was discharged from hospital, we found it very difficult to get information about head injuries and about services available for people with head injuries (other than G.F. Strong). As problems or questions arise, we now depend on the local Head Injury Association which has recently formed in our community, also by trial and error.

We found there was very little reading material about head injuries (what to expect, how to manage at home, etc.) from the hospital, physicians, and Public Health. Also, our local library has no reference material available. I found out through G.F. Strong that U.B.C. is part of the Provincial lending library system. We have since found out that our local college is part of the Provincial lending library system and hopefully our local city library will cooperate and supply reading material as well.

Again, through Social Services of the regional hospital, I was told to contact the recently formed "Head Injury Association" which was able to give us some written material.

3. LACK OF AWARENESS IN PROFESSIONAL MEDICAL PEOPLE IN OUR COMMUNITY TO HELP HEAD INJURED PEOPLE AND THEIR FAMILIES.

(a) *Re: Assessment Resources for the Head Injured Person*

At time of discharge from hospital, a request was made by our family physician for S to be assessed at G.F. Strong. There are limited professionals and resources to do an assessment in our northern community.

Between the time of discharge and mid-November, our daughter's progress was excellent. When we were contacted by G.F. Strong in November, local medical doctors (family physician, also a local neurologist) were of the opinion that an assessment at G.F. Strong was not necessary and time would be the major factor in determining S's recovery. Summer of 1988 was an approximate date we were given to have some testing done locally.

G.F. Strong advised us to come anyway, which we did. We found the assessment done at G.F. Strong to be very helpful in many ways.

More awareness is needed about head injuries in the medical profession locally as well as availability of more trained professionals to do some form of assessment until space is available at centres such as G.F. Strong for more comprehensive testing. There is a long wait for such centres and this leaves head injured persons unaware of their present capabilities. This results in many resources being unwilling to accept a head injured person or not knowing where to place him or her (i.e., school, employers). Assessments like those done at G.F. Strong give head injured persons and their families an overall view of where the head injured persons are currently at and can be instrumental in setting up a program to help provide the best quality of life available.

(b) *Lack of Professional Counselling*

Both group and individual counselling should be available through local resources for head injured persons and their families.

Suddenly families are put into an extremely stressful situation and this situation remains for some time. It generally takes two or more years to determine the extent of recovery of a head injured person. During that time, families often drift apart because of inability to cope, financial reasons and not knowing what the future may be. Studies have shown that no two people handle stress at the same time or in the same way. Counselling could help families cope with this major change.

During recovery, counselling is also crucial to head injured persons. They remember how they were prior to the injury and often have problems accepting their injury. They become angry and frustrated with this new situation. We have

found dealing with a teenager with head injuries to be a compounded problem. Helping S to cope with the death of her friends has been a trial and error situation with us.

Once again because of G.F. Strong, our family has been able to book counselling through the local Public Health Unit. This is to begin soon and we feel it will be very beneficial to all.

S was put into drug and alcohol counselling, which did not help. At that time, S still had some suicidal tendencies and a lot of depression from the loss of her friends in the accident. We were told that if she had been a runaway or in trouble with the law, i.e. shoplifting, she could have received the proper counselling. Words fail to describe my anger at this policy. After three sessions, S stopped going as she became very angry at this type of counselling. A visit to our family physician brought some bad news: There was a waiting list of approximately one year to see a local psychiatrist or psychologist. I was given the names of private counsellors and they were unable or unwilling to help. Through my employer, I contacted a community help group, as well as the local crisis centre, and got the same results. We resorted to trial and error at home.

With no proper counselling available, our family had to cope with S when she felt she too should have died with her friends and didn't feel life was worth living and still continue to cope with her depression. I don't know if what we did was right or wrong, but it has worked.

4. RE-ENTRY TO SCHOOL OF A BRAIN INJURED STUDENT

The next issue we tackled was school. Overall we found the local schools are not able to accept a head injured student. We were told S was entitled to an education but the schools did not know where to place her.

We have been able to find out there are programs for the mentally and physically handicapped students as well as for students with behaviour or attitude problems. These students are considered as "Special Needs."

In mid-October, a "home-bound" teacher came to our home two or three hours a week. With this help and the activity aides, S began to relearn to read and print, then write again. In November, on the recommendation of our family doctor, S attended remedial classes three hours a week mainly for social contact and to enforce the relearning of skills. She fatigued quickly and was not capable of more hours at that time.

G.F. Strong gave a detailed report of recommendations which we took to the school board in January. After a brief shuffling from person to person, we were told to register at S's "home" school. This school did not have facilities to accommodate S and we were told to go to another school with the same result.

After repeated visits and many phone calls to various people, we located a school which was willing to take S. Our daughter was to be integrated into school gradually, concentrating on reviewing English and math skills. Through this school, we were able to get a tutor (paid for by the Insurance Corp. of B.C.) who worked with S on the days S did not attend classes. S attended three classes (one hour each), three times a week, with the tutor coming to our home on the remaining two days for one-to-two hours each day, increasing the hours over the next two months. During this time, S was going to physiotherapy three times a week.

Each head injury is different. The rate and extent of recovery also varies. Studies recommend an individualized educational program for the head injured student. This type of program is currently available for physically handicapped students in our school district.

The school district must consider head injured students as a "Special Needs" group and budget for funds to provide individualized educational programs. As well, staff who will be teaching the head injured student should have special training. Head injured students require ongoing evaluation and often need teaching on a one-to-one basis.

5. FAMILY LIFE

As each member of our family has dealt with the situation in their own way and at varying times, it has been very difficult to have a "normal" family environment.

At one point, my husband wanted to admit me to the psychiatric ward as S enveloped my entire time and thoughts. This was true and later in January, 1988, I suffered a mental and physical breakdown. In the first few months after S's accident, my husband intentionally spent a lot of time away from home. He has found it extremely difficult to accept the fact that his little girl will not be "normal" anymore. I am so thankful S is alive. I can still look at her, touch her, talk to her. The parents of S's friends have only pictures and memories of their children.

Our son is resentful of the time and energy we have given S in the past year. This, too, has caused a lot of problems for our family. As S continues to progress, he tends to forget about her head injuries and doesn't understand them as well. Even though he is older than his sister, and we expect him to be more understanding, sibling rivalry exists. Initially other family relatives and friends expressed pity and some insinuated that it would have been better if S had died rather than have a less-than-perfect quality of life. The hardest thing to deal with was (and still is) pity that people openly express with words or through looks.

As S has no visible handicap, she has experienced loss of friends who have become impatient with her or who find her "immature" now. She also had to deal with ridicule and rumours being spread about her. This has caused extra stress and confusion for her -- something she is not capable of dealing with at this time.

Our daughter is in what I call a "time warp." She has had to re-live her entire life and this process continues as I write this. In the past year, S has had to re-learn how to crawl, walk, care for personal needs, read, write and many other things. The process is not yet complete. In the past year, she has had to grow up all over again. These are things most of us take for granted. The difference is S remembers what she was like prior to the accident. This re-learning process is very frustrating at times -- for S and for the family.

S has also had to give up sports -- such as baseball, which she loves -- because of poor co-ordination. She also has difficulty with balance and therefore cannot ride a bike. Roller skating, dancing, skating and skiing pose problems as well. We hope in time S will regain these skills.

Our daughter's personality has changed since the accident. Her social behaviour at times is unacceptable -- she can be rude, outspoken and unco-operative. She cannot deal with constructive criticism. Her mood swings are unpredictable.

After my breakdown last January, I was forced to realize that life did include things other than S. I have forced myself to spend time with other people and activities. It's difficult to do. I worry each time S is out of sight. I am not at ease until she or I return home. I have continued to work. This forces me to have outside interests and to take care of my personal appearance. S still requires a lot of attention. Time management becomes difficult -- household chores now have a very low priority. This causes friction at home from time to time.

6. SUMMARY

As more people are surviving traumatic brain injuries because of better medical facilities, other resources must be available after hospital discharge and rehabilitation.

Information must be made available. So little information is available to families as to what to expect during the recovery period and how to cope after hospital discharge. The best information I received was from a young man who helped at the accident scene and received head injuries five years ago. He told me of his experiences, and those of his family. Later on, the local head injury group was extremely helpful.

Awareness of head injuries for resources through public health, schools, medical personnel and the general public is required. Many resources exist and need to be trained to help head injured people. Home care of a handicapped person requires a large portion of the day. It has been very frustrating, tiring and a waste of valuable time having to find resources, then being passed on, only to be refused help again. Knowing that help does exist, one learns to be persistent, often annoying, to get this help. I have found it pays to knock on doors again and again, even threatening to camp out in offices, to get help.

Perhaps a "northen living allowance" should be given to doctors to encourage them to locate in northern communities, like the one we lived in at the time of the accident. Another alternative would be funding to enhance the recreational and arts facilities in these communities for this profession. Perhaps they would remain in their communities.

Counselling for families should be made available. Families are in shock for some time after a traumatic head injury and each family member deals with the situation in their own way and at varying times. This causes a lot of conflict and anger in a family unit.

We continue to remain optimistic, possible because of our new location and also because of a recent reassessment done at G.F. Strong. S has improved in most areas. We have found a local doctor in our new community who has worked with head injured patients and is familiar with the rehabilitation process.

As I write, the school year is about to begin. We have been told S is at an age where "Special Needs" programs are no longer available. She has been given an extension. We can only hope things will go well. We intend to monitor her daily progress and address problems as they arise. We are fully prepared to be persistent, even annoying, if required, to ensure she can continue with her schooling, using any and all resources available.

We do not make long-term plans anymore as too many variables seem to happen. However, some concerns we have are: will S be able to be self-sufficient in future years in terms of employment and be able to live on her own? Will she be responsible enough to get married? If so, can she have a family? (S suffered multiple internal injuries and doctors do not know at this time if she will be able to.) We are also very concerned about her long-term physical health.

Problems such as life insurance have come up. Our insurance company told us that S would probably not be eligible for any further insurance when her policy expires at age 21. (It is a juvenile policy which was to convert to whole life.) Medical insurance for out-of-country travel is not available.

Time will tell. It's a phrase that is used too often with a head injured person. With better resources and information, this time may not be so uncertain.

Listed below are some resources I think could help.

Regional Hospital and Physicians	Supply pamphlets about resources and services available, counselling to family at time of injury.
Public Health	Group support meetings, seminars by qualified professionals, counselling, public awareness.
Human Resources	Information and details of resources and services available.
Schools	Awareness of special needs, training of personnel, development of individualized education programs for head injured students.
Community Services and Recreation Facilities (pool)	Discounted rates for "outside" recommended physiotherapy and occupational therapy.
Manpower	Training programs.
Ministry of Health	Acknowledgment of special needs of head injured persons, more monies available for rehabilitation, family support, full utilization of local and regional services.

Thank you for your interest and thank you for taking the time to read this.

"Q"

August 31, 1988.

APPENDIX G

"JOHN: CASE EXAMPLE OF A HEAD INJURED CHILD"

Submitted by:

Dr. Melvin de Levie
Sunny Hill Hospital

December 16, 1987

JOHN: CASE EXAMPLE OF A HEAD INJURED CHILD

John was a talkative, outgoing nine year old who had a special talent for art work. He was described by his teacher as a good average student who liked to get his work done quickly so he could get outside and play soccer. John had almost completed grade four when he was involved in a car accident early one morning in May, 1987. John had been and is currently residing in Vancouver with his family.

Even though his skull was not fractured, John suffered a serious closed head injury. For the next three months he was seen intensively by the Sunny Hill Hospital rehabilitation team including medicine, nursing, physiotherapy, occupational therapy, speech/language pathology, psychology, recreation, and social work. He was also seen by the Postural Control Unit as specialized seating was required. Family members were with him around the clock until he began to talk again, almost two months later.

By the time John was discharged home at the end of August, 1987, he almost looked like his old self again. But he now had difficulty remembering things, such as what he had done earlier in the day or even earlier in the hour. He could carry on a conversation, but his speech was disorganized and vague as he used words such as "the whatever" while he searched for the proper words. John approached tasks in a disorganized fashion and had difficulty solving everyday problems. He had to concentrate harder in order to understand and remember simple directions or participate in a game, but due to the injury to his brain, he was easily distracted, lacked the ability to concentrate, and tired quickly.

Although he had successfully completed grade four, John returned back to his old class. In addition to having to repeat grade four, John also required one to one help outside of the classroom. Despite his decreased ability to pay attention and the many distractions in school, John had firmly-established classroom habits and attended well in the class. This took its toll, however, and John was exhausted by lunchtime. For this reason he was only able to attend school in the mornings. This created a problem since all of John's family worked and he could not be left on his own.

Unlike most children, John was very fortunate to be able to have a one to one community worker who picked him up from school at lunchtime, did activities with him in the afternoons, and took him to the hospital for his occupational and speech/language therapies. Minor balance problems were the only physical impairments remaining so John did not need to continue with physiotherapy since the community worker was able to oversee John's exercise program. The worker was also responsible for consulting with therapy staff and planning activities that would help John to use and reinforce skills practiced in therapy in real life situations.

Neither the community worker nor John's teachers were familiar with the unique problems typical to brain injured children. It was necessary for the hospital staff to be involved in educating the key people by providing literature, meeting on a regular basis and providing written suggestions for an activity program for John's afternoons.

This unexpected and traumatic injury has placed John's family under great stress, starting with their 24 hour bedside attendance during those initial weeks as he slowly regained consciousness. And now that he is home, they must try to understand why John does not do chores as well, is confusing to understand, and only attends school half-time, despite his remarkable physical recovery. It is therefore necessary to keep in close contact with the family months after John has been discharged from hospital in order to help them understand his problems and make adjustments at home in order to help him function more effectively. This has been difficult due to the family's poor grasp of English and has meant that John's sister has had to assume the role of intermediary between John's parents and the hospital staff, teachers, and community worker.

It is now four months since John was discharged from the hospital and he looks and acts very much like other boys his age. However he is still unable to attend school full-time. Starting in the new year, John will stay at school until 2:00, but will spend the additional hour outside the classroom with a tutor. Hopefully he will be attending school full time by the end of the school year. As he moves on to grade five he will continue to need one to one support outside the classroom and it will be necessary for a new set of teachers to be educated about the nature of his brain injury.

It is likely that for the next two to three years, there will have to be ongoing input to the school, speech pathologists, treating therapists, family etc. Since Sunny Hill Hospital is a Provincial resource and continuously admits new head injured children, therapy services will have to be transferred to the community. This will pose a problem since speech/language services for direct therapy are unavailable in Vancouver.

John and his family have been very fortunate to receive the amount of support they have had. This would have been quite different if funding had not been available from I.C.B.C. to cover the cost of the community worker and tutor. For example, without the community worker, the family would have had to arrange for John's care and transportation to therapy in the afternoons, and the physiotherapist would have had to continue to see John to monitor his exercise program. In addition, an important aspect of relearning cognitive skills, practising the skills in real life situations, would have been lacking. Instead, skills would have to be practised in artificial role-playing situations.

The story would also have been different had John lived outside Vancouver. There would have been additional hardship on the family during the initial weeks after the accident. Upon discharge, John would have returned to his community where there would likely not be anyone knowledgeable about the specific and often subtle problems the head injured child and his family must cope with.

Despite the marked progress John has made since his accident last May, his life and that of his family has been forever altered. It is fully expected that he will continue to recover, but the likelihood of John finishing school or holding down a job is now drastically reduced.